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ABSTRACT

This paper presents training recommendations for educators involved in the care of medically fragile children. The training guidelines span the preservice, inservice, and leadership training levels. The guidelines focus on: how personnel training can reduce fears related to serving children with specialized health needs, what type of curriculum should be developed for multilevel training of special educators and related service personnel, and how best practices training procedures can be disseminated statewide and nationally. Obstacles to obtaining the ideal and strategies for moving toward the ideal are identified. (JDD)

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Children with Complex Medical Needs: Implications for Training Personnel

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Defining the Issue

As increasingly sophisticated technology and medical knowledge promote the survival of infants and children with complex medical needs, more public attention has been focused on their care and education (Sirvis, 1988). Children with chronic illness and special needs now have access to appropriate public education. The passage of Public Law 94-142, the Education for All Handicapped Children Act, increased the number of students with complex medical needs within public school settings.

The unique educational services required for students with special health care needs have challenged more traditional approaches (Wood, Walker, & Gardner, 1986). These students for example, may need life or health support procedures during the school day. They may be technologically dependent or require administration of medication. The education of students with specialized health needs has raised many questions about appropriate training practices for special educators as well as who should perform needed services during the school day (Johnson, 1986; Osborne, 1984).

In 1988, a CEC Task Force representing school nurses, special educators and pediatricians convened to delineate the issues related to planning educational programs and related services for children with complex medical needs. Among the Committee's recommendations was that of using interdisciplinary teams to provide educational and health support for this population and to provide relevant training for educational and health care professionals.

The issues concerned with training personnel to care for children with complex medical needs in school settings was the topic of a February, 1990, U. S. Department of Education forum titled "Emerging Trends in Special Education: Implications for Training". The report described in this document summarized the deliberations of the multidisciplinary panel assembled to address training recommendations for educators involved in the care of medically fragile children. The training guidelines span the preservice, inservice and leadership training levels.

The critical questions identified by the panel included the following:

1. How can personnel training reduce fears related to serving children with specialized health needs?

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2. What type of curriculum should there be for multilevel training of special educators and related service personnel who serve children with complex medical needs?

3. How can "best practices" training procedures for educators and related service personnel working with children with complex medical needs be disseminated statewide and nationally?

Alternative Solutions

For each of the above questions, the panel proposed solutions. Although these are "ideal" solutions, they represent approaches that should be considered when mapping out a comprehensive training plan to adequately address the educational needs of medically fragile children.

1. How can personnel training reduce fears related to serving children with specialized health needs?

A key element in reducing fear is education. Through in-service and preservice training teachers, administrators and related health personnel can become sensitized to the range of medical needs as well as learn medical terminology, acquire knowledge of equipment and procedures as well as gain an awareness of warning signs (e.g., breathing difficulties, seizures), that are potentially anxiety-producing for the professional.

A second element in fear reduction is to define this population in a more realistic and dynamic way. The term "medically fragile child" is often used, yet can convey an impression that the child might break. The term "medically fragile" may in fact increase a professional's fear of the child or child's condition. Suggested is a more appropriate term that may serve to challenge the professional, that is, "children with complex medical needs". Within this definition, four broad categories can be included: (a) technology assisted, (b) special considerations (e.g., asthma or diabetes) and (d) communicable diseases.

2. What type of curriculum should there be for multilevel training of special educators and related service personnel who serve children with complex medical needs?

A core curriculum that addresses the terminology, etiology, implications, and interventions associated with providing services to this population is needed for all levels of training from the Associates through the Doctoral level. In addition, selected components of the curriculum should be taught at the in-service level. Often the in-service training would be child or problem-specific since the professionals working in the field would be encountering specific problems in their work with children. Regardless of the level of content, the curriculum

must have an interdisciplinary approach within the framework of a family-centered orientation. The design and delivery of the curriculum should involve the appropriate disciplines. The interdisciplinary focus would include medical, educational and psychosocial components. Varying methods of learning strategies should be employed to afford trainees the opportunity to observe and practice procedures involving equipment and appropriate medical care.

While the overall focus and philosophy of the core curriculum would be the same across training levels, training approaches would differ. At the Associates and in-service level, training would address resources for child-specific as well as general educational needs in the area. Recommended is a case management training approach which would collaborate health and education to assist providers who are experiencing the challenges of working with children with specialized needs.

At the preservice level (Bachelors and Masters), specialized courses should be offered in addition to basic requirements. Existing courses can be infused with the curriculum content on a multi-level basis. Doctoral level training should include both formal course work and internship opportunities that provide hands-on experience. An integral leadership training component would be that of research training in the field.

3. How can "best practices" training procedures be disseminated statewide and nationally?

An important aspect of developing a core training curriculum is its implementation at the state and national level. First, best practice within the curriculum must be defined in a multi-disciplinary way. Since the proposed curriculum is designed to be both adaptable and interdisciplinary, it is expected that there will be different emphasis with regards to best practices depending on state needs. Systematic dissemination within states is most likely to take place through efforts of state education and health care departments. Nationally, best practices can be described an demonstrated through interdisciplinary forums, conferences and national training institutes.

Obstacles to Obtaining the Ideal

Successful implementation of multilevel training that prepares educators and related service providers to work effectively with children with complex medical needs requires overcoming several barriers. One such obstacle is attitudinal,that is,fear of working with medically involved children. For example, professionals' fears of not knowing appropriate care procedures or not recognizing distress signs may interfere with service delivery.

Another formidable obstacle involves the availability and sharing of interdisciplinary resources. A requisite of the

proposed core training curriculum is the utilization of expertise of special educators, medical health providers and mental health specialists. Finding ways to link these resources is central to curriculum development and implementation. The availability of the financial resources needed to support such training is a potential obstacle. At both the state and national level creative efforts must be made to support multilevel training.

Strategies for Moving Toward the Ideal

There is a clear need for training professionals to respond to the educational challenges associated with children with complex medical needs. Such training must be multilevel and collaborative across disciplines. Moreover, the training must be adaptable to fit the needs of the educator or service provider.

How can such training be developed and provided? How can the barriers to implementing and disseminating this training be overcome? These questions must be addressed at both state and national levels.

If the curriculum and training is to be truly interdisciplinary, then efforts must be made to bring representative professional groups together to promote these efforts. The newly created Federal Interagency Coordinating Council (FICC) is one example of possible interface among agencies. Collaboration can be encouraged via interdisciplinary conferences in which workshops and panels promote dialogue and planning across disciplines. Finally, federal agencies that grant training funds must identify training needs in this area as pertinent to their priorities. There must be intercollaborative planning and pooling of funds to support and sustain such training at the state and local level.

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